

# Fighting the stigma caused by mental disorders: past perspectives, present activities, and future directions

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*People who live with mental illnesses are among the most stigmatized groups in society. In 1996, in recognition of the particularly harsh burden caused by the stigma associated with schizophrenia, the WPA initiated a global anti-stigma program, Open-the-Doors. In 2005, a WPA Section on Stigma and Mental Health was created, with a broader mandate to reduce stigma and discrimination caused by mental disabilities in general. In light of these important developments, and the growing public health interest in stigma reduction, this paper reflects on the past perspectives that have led us to our current position, reviews present activities and accomplishments, and identifies challenges that the Section members will face in their future efforts to reduce the stigma caused by mental disorders.*

**Key words:** Mental health related stigma, stigma reduction, discrimination, Open-the-Doors anti-stigma program

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Having now passed the 12th anniversary of the WPA Global Program to Fight Stigma and Discrimination Because of Schizophrenia, and the third year of operation of the WPA Scientific Section on Stigma and Mental Health, it is timely to reflect on the past perspectives that have led us to our current position, review present activities and accomplishments, and identify challenges that the Section members will face in their future efforts to reduce the stigma caused by mental disorders.

## PAST PERSPECTIVES

The pejorative use of the term *stigma*, reflecting a mark of shame or degradation, is thought to have appeared in the late 16th and early 17th centuries. Prior to that, *stigma* was more broadly used to indicate a tattoo or mark that might have been used for decorative or religious purposes, or for utilitarian reasons, such as a brand placed on criminals or slaves so that they could be identified if they ran away and to indicate their inferior social position. The evolution of the term notwithstanding, negative societal responses to the mentally ill have been ubiquitous throughout history – a situation that has persisted through changing concepts of mental illness – even through the rise of medical theories and biologically-based explanations for most mental disorders (1,2).

Contemporary notions of stigma are grounded in sociological and psychological theoretical traditions. For example, our modern understanding of stigma and its effects stems largely from the seminal work of Erving Goffman, conducted in the early 1960s. In *Stigma: notes on the management of spoiled identity*, Goffman describes the damaging effects of stigma, which reduces the bearer from a whole person to one that is irredeemably tainted (3). In Goffman's

view, mental illness was one of the most deeply discrediting and socially damaging of all stigmas, such that people with mental illnesses start out with rights and relationships, but end up with little of either (4). Goffman was deeply critical of mental hospitals for their stigmatizing and anti-therapeutic effects (5) and, along with contemporaries such as Szasz (6) and Scheff (7), reinforced the perception that stigma was rooted in the nature of psychiatric diagnosis and treatment. From this original focus on stigma as a by-product of the social organization of psychiatry, contemporary social theorists have taken a much broader, ecological view; one that recognizes the complex interplay of social-structural, interpersonal and psychological factors in the creation and maintenance of stigma (8,9). From this perspective, stigma is pervasive, pernicious, and resistant to change and, to be successful, anti-stigma programs must be comprehensive, multi-pronged and directed to individual, interpersonal, and system-level determinants.

Psychological theories have helped us understand how cognitive and attributional processes at the social-psychological levels lead to the development and maintenance of the negative and erroneous stereotypes that form the internal scaffolding for stigmatized world views. Attribution theory provides a particularly useful framework for understanding stigma and for targeting anti-stigma interventions. Attribution theory traces a path from a signaling event (a label), to an attribution (or stereotype), to an emotion (negative), and finally to a behavioural response (discrimination). In the case of mental illness, extensive research has confirmed that people who hold moral models of mental illness – those who believe that the illness is controllable, or that people with mental illness are to be blamed for their symptoms – are more likely to respond in an angry and punitive manner. In theory, it is possible to replace incorrect attributions to reduce stigma and discrimination; however, it



has not yet been possible to definitively link improvements in knowledge or attitudes to behavioural change. The approaches that have been most successful in improving knowledge and attitudes (but not necessarily behaviours) have combined active learning with positive contact with people who have a mental illness. Fact-based and protest-based approaches have been less successful, though it has been difficult to generalize across studies with different outcomes, or determine whether changes in knowledge or attitudes have improved the lives of people with mental disorders (10,12).

## PRESENT ACTIVITIES

Over the last decade, public health interest in both the burden of mental illness and the hidden burden of mental health related stigma has grown. Organizations such as the World Health Organization (13-16), the WPA (17,18) and the World Association for Social Psychiatry (19), to name a few, have all recognized stigma as a major public health challenge. Growing support for stigma reduction is also evident in the number of government declarations, mental health system reviews, and action plans that have highlighted the disabling effects of stigma and the importance of reducing discrimination (20-23). Large-scale nationally coordinated population-based anti-stigma initiatives have also emerged during this time in Australia (24), New Zealand (25), the United Kingdom (26) and Japan (27).

In 1996, the WPA initiated a global program to fight stigma and discrimination because of schizophrenia. In the ten years since its inception, more than 20 countries have joined the WPA's *Open-the-Doors* global network, making this the largest and longest running anti-stigma program to date. Participating countries (in order of enrolment) include Canada, Spain, Austria, Germany, Italy, Greece, the United States, Poland, Japan, Slovakia, Turkey, Brazil, Egypt, Morocco, the United Kingdom, Chile, India, Romania, with several more in the planning phases. A brief overview of the program is presented in a previous issue of *World Psychiatry* (28). Detailed results for the first eighteen countries are reported in the recent book *Reducing the stigma of mental illness* (18).

The *Open-the-Doors* program is unique among anti-stigma efforts in that it reflects the work of an international consortium of members, all of whom endorse three core principles. The first is that program goals and objectives are to be developed from the priorities and needs of people who live with schizophrenia, garnered from quantitative and qualitative needs assessments and realized through their active participation in all aspects of program development, implementation, and evaluation. Second, local programs are to encourage broad participation from community members, making a concerted effort to move beyond the mental health sector. Early experience showed that it was particularly important to include members of target groups on local planning committees. Third, recognizing the pervasive na-

ture of stigma, planning teams are committed to creating programs that are sustainable over the long term, often emphasizing smaller focused efforts which have greater long-term viability. Following the planning process that has been outlined, it typically takes 12-18 months for a group to have their program up and running.

A wide number of groups have been targeted by local programs to be recipients of anti-stigma interventions. Their diversity highlights the pervasiveness of stigma both within and across cultures, as well as the importance of adopting a program design process that allows for culturally relevant content. At the same time, because target groups are based on the priorities of local consumers and family members (at least those that could be most feasibly addressed), they give us a partial glimpse onto some of the most common sources of stigma experienced by people living with schizophrenia worldwide. Of the first eighteen sites profiled by Sartorius and Schulze (18), for example, fifteen targeted general practitioners and other health care personnel, making this the most frequent target group. Other target groups included primary and secondary school students (n=13), journalists and mass media (n=13), psychiatrists and mental health professionals (n=12), people who have schizophrenia (n=11), family and friends of people with schizophrenia (n=11), members of the general public (n=11); members of the religious community and clergy (n=6), government workers and non-governmental agencies (n=5), businesses and employers (n=5), medical students (n=3), and judicial and law enforcement personnel (n=2).

In contrast to the growing interest in stigma reduction, and a rich theoretical literature pertaining to stigma and discrimination, the evidence base needed to support stigma change is underdeveloped (29). Indeed, an important accomplishment of the WPA global program has been to increase the production of knowledge and practical experience concerning *better* practices in anti-stigma programming in both developed and developing countries. To date, the program participants have implemented over 200 interventions, ranging from speaker's bureaus and contact-based educational programs (n=12), to protest-based programs (n=6), to mass media campaigns using television or radio (n=10), and novel applications of drama and the arts, including consumer-run theatre productions and large benefit concerts featuring international celebrities (n=8). Thirteen of the first eighteen sites have already published their results in scientific journals (18) and four sites have now analyzed their data cross-culturally (30,31).

A third important contribution has been the development of a multi-disciplinary interest in the implementation and evaluation of anti-stigma programs. Previous research has tended to be theoretical and discipline-specific. Program members have collaborated to host three international scientific conferences focusing on the science of stigma reduction, giving important impetus to this emerging field. The first *Together Against Stigma International Conference* was held in Leipzig in 2001, hosted by the German *Open-*



*the-Doors* site. The second was held in Kingston, Canada in 2003, and the third was held in Istanbul, Turkey in 2006. Reviewing a decade of progress, it is possible to see how the field has developed from the presentation of results from initial needs assessment surveys, through goal-based evaluation results, to large-scale cross-cultural comparisons involving international consortia of researchers.

In order to build and expand on this momentum, program members have recently developed a WPA Scientific Section on Stigma and Mental Health. The Section was approved by the WPA General Assembly at the 13th World Congress of Psychiatry held in Cairo, Egypt in 2005. Since its inception, the Section has grown to include some sixty researchers from 25 countries.

## FUTURE DIRECTIONS

An important goal of the Section is to continue the momentum created by the *Open-the-Doors* program and enlarge the network to include new program sites. Toward this end, Section members will continue to provide training opportunities and materials through workshops and special courses organized at WPA and other international and national congresses. Members are also actively involved in the development of international research consortia devoted to the study of particular aspects of mental health stigma, such as consumer experiences with stigma and discrimination. The development of the specialized tools needed to support these efforts has been underway for some time.

With increasing recognition of the public health importance of stigma, and growing knowledge about how to fight stigma and discrimination both locally and internationally, the future of applied stigma research holds a number of exciting prospects for Section members. Much of the activity of Section members has been on fighting stigma and discrimination because of schizophrenia, as this was the original impetus behind the global program. The rationale for this choice was based on the knowledge that the stigma associated with schizophrenia is particularly harsh and intimately linked to fears and misconceptions concerning violence and unpredictability. The importance of focusing on a specific illness, rather than mental illnesses in general, was considered in light of the need for a clear program focus, the fact that the general public uses schizophrenia as a paradigm for mental illness (often describing psychotic and disorganized behaviours as characteristics of all mentally ill), and the idea that any gains made in this difficult area would certainly be useful to those working to eradicate stigma related to other mental illnesses (18). Given the broader interests of the members, also reflected in the broader mandate of the Section, an important focus for future work will be to develop international anti-stigma research consortia pertaining to other highly disabling mental illnesses, such as mood and anxiety disorders.

A clearer understanding of the cross-cultural nature of

stigma and discrimination experienced by people living with mental disorders will also be an important avenue for future investigation. Instruments are now available to quantify the scope and impact of stigma experienced by people with a mental illness (32-34). However, much remains to be done to validate their use in different cultural settings and to ensure they are sensitive to change. To be judged effective, future anti-stigma interventions must do more than change public knowledge or attitudes toward the mentally ill. They must also fundamentally change the stigma experiences of people who live with mental disabilities. In developing an evidence-base for anti-stigma programs, then, consumer perspectives will be of increasing consequence, not only to identify targets for program activities, but also as an evaluation yardstick against which program improvements can be judged.

Finally, although people with mental illnesses are among the most stigmatized groups in society, mental illnesses are not the only stigmatized health conditions. Leprosy, HIV/AIDS, tuberculosis and cancer are among the many stigmatized health conditions for which advocates have battled social stigma, some more successfully than others. It is important that lessons be shared across groups. This will not only improve our understanding of the general social and psychological conditions that give rise to health-related stigmas, but also allow us to learn from and build on each other's successes and avoid each other's failures.

The members of the WPA Section on Stigma and Mental Health are committed to advancing scientific knowledge to improve social inclusion for people with mental illnesses and their families. Through the *Open-the-Doors* network and other collaborative means, they are developing international scientific projects, taking an active role in WPA-sponsored meetings and World Congresses, and contributing to the scientific literature dealing with mental health stigma and discrimination.

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